Involvement of family members in life with type 2 diabetes: Six interconnected problem domains of significance for family health identity and healthcare authenticity

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Abstract

Objectives: Family involvement plays a key role in diabetes management. Problems and challenges related to type 2-diabetes often affect the whole family, and relatives are at increased risk of developing diabetes themselves. We highlight these issues in our objectives: (1) to uncover specific family problems associated with mutual involvement in life with type 2-diabetes and (2) to analytically look at ways of approaching these problems in healthcare settings.

Methods: Qualitative data were gathered in participatory problem assessment workshops. The data were analysed in three rounds using radical hermeneutics.

Results: Problems were categorized in six domains: knowledge, communication, support, everyday life, roles and worries. The final cross-analysis focusing on the link between family identity and healthcare authenticity provided information on how the six domains can be approached in healthcare settings.

Conclusion: The study generated important knowledge about problems associated with family involvement in life with type 2 diabetes and about how family involvement can be supported in healthcare practice.

Keywords

Family, involvement, type 2 diabetes, health identity, authenticity

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Introduction

Family involvement plays a key role in diabetes management, and the importance of family approaches has received increasing recognition.^{1,2} However, family involvement is a complex matter, often characterized by unclear structural relations and contrasting needs and expectations within the family. Supportive and obstructive behaviours frequently cooccur.^{3,4} For this reason, more family involvement is not always beneficial.^{3,5} People with limited resources are especially vulnerable to the harmful aspects of family involvement.⁶ Close relatives often describe discomfort with the perceived need to monitor the person with diabetes as well as confusion about their role in diabetes care; these feelings often result in unintended family conflict.⁷ Studies have also shown that relatives tend to have concerns about diabetes that are often not voiced.⁸

In families where a member has type 2 diabetes, relatives have a significantly higher risk of developing type 2 diabetes.^{9–11} A major obstacle to constructive intra-familial communication about prevention, familial risk and risk reduction behaviours is a lack of perceived disease relevance.^{12,13} Godino et al.¹⁴ reported that people's motivation to engage in risk-reducing health behaviours or to undergo screening is dependent on whether or not they are aware of their susceptibility to a given disease.

One way of approaching the challenges of intra-familial communication is to look at contextual conditions for developing a shared family identity. When family members experience

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Creative Commons Non Commercial CC BY-NC: This article is distributed under the terms of the Creative Commons Attribution-NonCommercial 4.0 License (http://www.creativecommons.org/licenses/by-nc/4.0/) which permits non-commercial use, reproduction and distribution of the work without further permission provided the original work is attributed as specified on the SAGE and Open Access pages (https://us.sagepub.com/en-us/nam/open-access-at-sage). considerable stress associated with their caregiver role, it is the mutual understanding of roles and interconnected relationships that affect how these individuals interpret and respond to the role.¹⁵ Viewing family identity as the features that differentiate the family from other important entities and constitute a unique set of potentials and limitations enables us to focus on how identities are built within the family through a mutual differentiation process.¹⁶ Studies on identity have shown that familial relationships play a predominant role in how health is perceived and integrated into everyday life and self-perception.^{17,18}

We need to know more about how to approach families in order to support a heightened level of positive involvement and support – while acknowledging that this involvement has to be sensitive to a myriad of potential family characteristics. This article is based on data gathered in participatory problem assessment workshops conducted with families and healthcare professionals separately. Based on the background and challenges above, the objectives of this article are to uncover specific family problems associated with mutual involvement in life with type 2 diabetes and to analytically consider possible ways of approaching these problems.

Methods

Five 3-h workshops with people with type 2 diabetes and their relatives (n=16/22; Tables 1 and 2) were organized in two regions in Denmark. Each workshop was organized as a series of different dialogue exercises, where the participants were split into groups - sometimes with their family and sometimes with other relatives/people with diabetes. Besides the person with type 2 diabetes, the participants were primarily spouses and adult offspring. The workshops were semistructured in the sense that the research group facilitated each group session, keeping it focused on topics related to family issues and everyday life with type 2 diabetes. The families volunteered for the workshops after receiving an invitation from local healthcare professionals working with type 2 diabetes. Based on the researchers' experience with data saturation when doing participatory workshops, five workshops were initially planned and we stopped recruited participants when we had enough for these five workshops. After the fifth workshop, it was clear that no new themes had emerged since the third workshop and the researchers agreed that data saturation had been achieved. When selecting people with type 2 diabetes for each workshop, the diversification criteria were gender, age and years since diagnosis. Additionally, we wanted to include different kinds of relatives in each workshop.

Five 2-h workshops with healthcare professionals (n=37; Table 3) were organized in the same two regions. Patient education professionals working with type 2 diabetes were invited, and all volunteers were assigned to workshops. The semi-structured workshops focused on the participants' experience with family involvement and used dialogue tools

		Ν
Gender	Male	6
	Female	10
	Total	16
Age	50–55	3
	55–60	3
	60–65	2
	65–70	5
	70–75	3
	Total	16
Years since	0	4
diagnosis	I—5	3
	5–10	2
	10-15	3
	>15	4
	Total	16

Table 2. Characteristics of relatives.

		Ν
Gender	Male	9
	Female	13
	Total	22
Relation	Wife	6
	Husband	7
	Son	3
	Daughter	5
	Sister	I
	Total	22
Age	<20	4
	20–40	3
	40–60	8
	>60	7
	Total	22

in a variety of group formations. The workshops were facilitated by the research group. After the fifth workshop, it was clear that no new themes had emerged since the fourth workshop and the researchers agreed that data saturation had been achieved. The diversification criteria when selecting participants for each workshop were age, professional background and years of experience with patient education.

All workshop sessions were recorded and transcribed verbatim. The data were iteratively analysed and categorized using Rasmussen's¹⁹ radical hermeneutics, which are guidelines for content analysis that, by virtue of being a combination of hermeneutics and constructivism, manages to be empirically true as well as theoretically complex. Radical hermeneutics focuses on keeping a balance between theory, method and data, as an interconnected process that requires a constant focus on how these elements influence each other. Therefore, the theoretical elements are presented here in the

 Table 3. Characteristics of healthcare professionals.

		Ν
Age	<30	I
	30-40	8
	40–50	13
	50–60	10
	>60	5
	Total	37
Professional	Nurse	20
background	Physiotherapist	4
	Dietician	4
	Administration	7
	Social educator	2
	Total	37
Experience with	<5 years	12
patient education	5–10 years	8
	10–15 years	7
	15–20 years	7
	>20 years	3
	Total	37

'Methods' section as they are integral parts of the analytical approach rather than the background. The use of radical hermeneutics also entails a constant fluctuation between analyzing and interpreting, which means that it is sometimes necessary to present interpretive aspects while presenting the analytical results.

The methodology entails three steps of analysis. The first step involves a reading of the data with a view to observing how specifically selected guiding differences are observed in the data. This observation in itself constitutes an interpretation rather than a description, and its task is to reduce the complexity of the data. Elements within the scope of the guiding differences selected by the interpreter are extracted from the data. The second step involves making these elements the subject of interpretation as an observation of the differences employed. The third step involves interpreting the sum of these differences.¹⁹ In the concrete analysis, the first reading disclosed six interconnected problem domains pertaining to: knowledge, communication, support, everyday life, roles and worries. In the second round, these domains were analysed and interpreted separately, and in the third round the findings in the six interpreted domains were analysed transversely, using the health education theories on healthcare authenticity and family health identity described below. Applying theory to the third round of analysis constitutes an important methodological step, as it deliberately refocuses the vantage point of the analysis. The choice of theory is based on the findings of the first two rounds of analysis and our desire to re-focus the analysis on how we should approach the uncovered problems in healthcare practice.

Using radical hermeneutics is a way of systematically getting deeper and deeper into the analysis of the empirical

data at hand, while at the same time being constantly aware of what choices were made earlier in the process – and using these earlier steps in the final interpretation of the data. In the process of the three rounds of analysis, it is important to be aware of the blind spots within the analysis. Making the guiding differences explicit is a way of observing your own observations in the analysis, and as such it is an alternative way of approaching traditional methodological parameters like relevance, validity and reflexivity.¹⁹

Theoretical framework

The concept of authenticity has not previously been explored in studies of family involvement and healthcare practice. Contributions to the conceptualization of authenticity largely stem from the education literature.²⁰ In a review of authenticity in teaching, Kreber et al.²¹ discussed authenticity as a multidimensional concept based on genuine care. Informed by Taylor's²² 'ethics of authenticity', Kreber et al.²¹ foregrounded the importance of engaging people in genuine dialogue around ideas that matter. Barab et al.²³ described authenticity as an emergent process that is actualized through individuals' participation in tasks and practices of value to themselves and to a community of practice. In doing this, they drew upon Dewey's²⁴ classic theories of experience and of how an idea is always to be located in its consequences.

The definition of health identity is based on Waterman's²⁵ theories on delineated self-definitions, Taylor's²⁶ social imaginaries and Luhmann's²⁷ expectational structures. The definition of health identity used in the analysis is: 'People's observations and expectations concerning their own health, their knowledge about health and in what ways their health is related and comparable to the health of others'.¹⁸ People's health identity is developed on the basis of individual observations (and consequent meaning making) of communication and is expressed through expectational structures and social imaginaries that have an impact on health values, health beliefs and health choices. Health identity functions as a way of orientation and navigation in the complexities of health communication, health information and possible health behaviours.^{17,18}

The Danish Research Ethics Committee has approved the study (reference number H-15006088). All participants provided informed written consent.

Results

The results are presented in two parts in accordance with the progression of the analysis.

First and second rounds of analysis: what are the problem areas and what do they contain?

The first round of analysis focused on extracting all items of relevance to family involvement. The analysis disclosed six problem domains that were then analysed separately. Many of the quotes below have figured in several of the six categories and have therefore been part of the analysis in all of the relevant problem domains. This makes the data coherent and flexible and helps to illuminate the fact that all six categories are strongly interconnected in family life with type 2 diabetes. If one domain is affected, it is very likely that the other domains will be affected as well.

Difficulties sharing knowledge in the family. In the family workshops, knowledge was often the first topic discussed. Most families had experienced frustration in relation to knowledge, and many sources of frustration were associated with ways of sharing knowledge in the family:

The area where I find the biggest differences family-wise, is that my children focus much more on my heart condition than on my diabetes. They believe that the heart thing can kill me. The diabetes could also kill me, but they don't know that. I really wish that they would get a more realistic understanding of what diabetes is – simply by getting some proper information. But that of course requires a basic interest in getting the facts. It has to be made interesting. They don't get how serious it is. (Man with diabetes – workshop 2/participant 7)

This lack of knowledge about the seriousness of type 2 diabetes was a common theme among relatives as well as people with diabetes. This lack of perceived seriousness or relevance has implications for whether information and knowledge are deemed sufficiently important to acquire and how actively any acquired knowledge is disseminated within the family.

Many healthcare professionals mentioned that families often lack knowledge about the degree of heritability and thereby about the possibilities for preventive actions and early diagnosis. In many families, this lack of knowledge means that relatives tend to ignore risks:

There really isn't a great deal of knowledge about the hereditary factor in the families. I find that interesting and really important to communicate to the whole family. When someone in the family has or is diagnosed with diabetes, then it really involves the whole family. Then they can take precautions and maybe change a few things in their life. (Healthcare professional – workshop 1/participant 3)

Intra-familial dissemination of knowledge was a key point of focus for the healthcare professionals. They described uncertainty about how knowledge was shared within the family when they only had direct contact with the person with diabetes. Getting to know the whole family and family members' specific ways of sharing or not sharing knowledge was a challenge and a potential barrier to creating involvement in the family.

Inadequate intra-familial communication. Sharing of knowledge is closely related to the communication structures in the family. Many families experience serious communicative problems that have various manifestations. For some families, the problem materializes as a case of too little communication about type 2 diabetes:

We have no togetherness anymore. We have no real relationship. We don't have anything at all. We don't talk about the problems like we should – and that's probably our biggest mistake? We don't talk at all. She just takes her injection in her thigh or her stomach, and that's it. (Husband – workshop 3/participant 2)

In other families, the problem is the exact opposite, in that diabetes-related communication takes up too much space in everyday life, thereby creating a situation where other aspects of life are neglected:

Sometimes I think it's been too much and then I've told her: 'You've got to talk to someone else about these things. You have to remember that I'm your daughter' It just takes up so much space in her life that she often cannot talk about anything else. (Daughter – workshop 3/participant 4)

Communication structures, and all the expectations and imaginaries that are tangled up in them, are extremely complex. These complexities are then further illuminated when the families are faced with chronic disease. Healthcare professionals told us that communication in families with type 2 diabetes often ends up as a negative process that is exceedingly difficult to break out of:

We often see that lots of things remain unsaid. It can be really hard for the one with diabetes to express his wishes about what kind of help and support he really needs. Often they don't know how to talk about this at all, and then it just gets worse and worse – we have to help them create the right dialogue. (Healthcare professional – workshop 3/participant 1)

These communicative complexities makes the situation increasingly difficult to grasp and manage for the family as a whole and for the family members individually – creating a de-motivating communicative gridlock.

Difficulties understanding and accepting new familial roles. The daughter in the quote above serves as a good example of the role confusion that often arises in families faced with type 2 diabetes. The relatives often find it difficult to understand and to fit into the role as someone closely related to a person with type 2 diabetes. For the person with diabetes, accepting or not accepting the role as a person with a chronic disease is a common theme. Role frustration is highlighted in social interactions where changes in family structures and interdependent roles are illuminated:

What we really hate when the family is gathered, is when we end up talking about disease. I'm not f***ing sick! Not in my daily life. I have that f***ing diabetes and a back condition. But apart from that I'm not sick. If you talk about it all the time you get really tired of it. (Man with diabetes – workshop 2/ participant 5)

Several healthcare professionals mentioned that the roles that seem confused and perhaps inappropriate after a family member is diagnosed with type 2 diabetes are in fact the same roles that have been carefully negotiated over time. These roles and the conflicts between them are amplified in the new family setting that is created when a family member is diagnosed with type 2 diabetes:

All the roles they've built up over time in their relationship become really exposed. (Healthcare professional – workshop 5/ participant 4)

Many of the family members in the workshops expressed a need to cling to existing roles while not at all understanding the new expectations and imaginaries attached to these roles:

Well, I'm still exactly the same person. A lot of people around me think they have to treat me differently and take care of me all of a sudden. They call and ask me, what I can and cannot eat. Don't make all these changes! I can always eat some of it – and who cares if I go home a little bit hungry? (Man with diabetes – workshop 1/participant 1)

Trying to make sense of all these old and new interconnected roles within the family is a common source of frustration and misunderstanding.

Frustrations with everyday routines and attempts to maintain a sense of normality. Everyday life is affected when type 2 diabetes enters into the equation, either in the form of radical changes particularly in diet and exercise or in the form of an unwillingness to apply these changes and the frustration this brings about:

Sometimes I have to cook three different meals and that's really frustrating – also because I really crave the fatty food. But that's not good for me and when I sometimes do eat the fatty food I really feel it. (Woman with diabetes – workshop 5/participant 1)

This woman is trying to adapt to a new and healthier lifestyle, while at the same time trying to maintain a kind of everyday normality. Many of the families talked about the issue of not wanting diabetes to take over everything in the family – which means they have to create a lot of highly difficult and potentially harmful everyday practices in order to maintain a sense of the normality they had before type 2 diabetes entered the family. Another example of families trying to circumvent the everyday hassles with diabetes is this woman preventing herself from shopping so she will not have to deal with having unhealthy food in the house:

For a long period I had to send Johnny to the supermarket, because then I knew that we wouldn't buy any cakes or stuff like that. (Woman with diabetes – workshop 3/participant 1)

For healthcare professionals, gaining access to the actual everyday life of these families is important, but also a concrete challenge:

In the healthcare system we only see fragments of people's real everyday life. But the relatives are together with our patients all the time. They see a lot more of the nuances and they experience all the ups and downs first hand. They are the real experts who can tell the stories that give us the full picture. (Healthcare professional – workshop 3/participant 5)

Healthcare professionals agree that a thorough understanding of everyday mechanisms and practices in the individual family is crucial to their work with the person with diabetes and to their prerequisites for creating family involvement and positive structures for preventive actions and early diagnosis among relatives. Knowledge about how information and knowledge are shared, how the family communicates and how they construct and adapt to roles is difficult to acquire without access to the whole family and their everyday practices.

Difficulties understanding how to mutually support each other. Understanding how to be supportive without being intrusive or controlling – and particularly understanding when to support and when not to actively support – is a central issue discussed by family members as well as healthcare professionals. The data show that support is a complex, multifaceted and very prominent aspect of family life with type 2 diabetes. In some cases, lack of support is perceived as lack of affection:

If they didn't react at all then I wouldn't be able to see that they really care. That they react in a thoroughly annoying way is another side of the matter. (Man with diabetes – workshop 1/ participant 3)

The person with diabetes often finds it difficult to ask for support and equally difficult to refuse support. For the relatives, it is often difficult to determine when to give support and when to let the person with diabetes manage on his or her own. Unfortunately, the families report many instances where conflicts and breakdown in communication on how to support resulted in opting out of giving support altogether:

I've tried to meddle in the things I think he's doing wrong. But that has not come out to my advantage. Since then I haven't meddled at all. He takes care of himself and that's just fine. (Wife – workshop 4/participant 2)

In other families, attempts at giving support are ongoing – but part of a process in which the attempts become increasingly misguided and negative:

I don't think he worries about me at all.

Yes I do! It worries me a lot that you won't listen to anything I say. Every time I say something, you just say that it doesn't

matter. But I know that I'm right and I know that they tell her the same things at the hospital. And then I just say 'I told you so'... I really want to help her, but I think she misunderstands me every time we talk about things. It's for her sake 'For God's sake don't buy all those cakes'. It really is for her sake. I really worry about you. It's all really going down the drain right now. I don't know what to do. (Woman with diabetes and her husband – workshop 3/participants 1+2)

This husband told us how he has tried to be supportive – without any success at all. The quote says a great deal about the problems connected with working out how to provide support as well as about how unsuccessful attempts at giving support add to the accumulated frustration, fear and worry.

Mutual worries often remain unspoken and unrecognized. As illustrated in the quote above, worries, concerns and fears are manifold and potentially attached to all aspects of family life with type 2 diabetes. A common worry is that the older generation's bad habits are being adopted by the younger generation. Many parents express concrete worries about their children's health behaviour:

Well, we've raised them and given them some bad habits, I guess. I've always been in charge of what we eat, so it's basically my fault. I guess that's just the way it is. (Wife – workshop 1/ participant 5)

It is important for healthcare professionals to take the worries of relatives seriously. They often talk about how the worries relatives have are significantly different from the worries the person with type 2 diabetes has:

It's often the other family members who bring the really serious stuff to the table. (Healthcare professional – workshop 1/participant 5)

Involving relatives in life with type 2 diabetes is important because their worries often remain unspoken and hidden from the person with type 2 diabetes:

The husband is often really annoyed with his wife when she tries to interfere too much with his life. Then I tell him that: 'it's just because she's really worried about you. She doesn't want to lose you! Have you thought about that?' But they never talk about these things. If they ever talk about diabetes it is only about practical issues. (Healthcare professional – workshop 2/participant 5)

Putting equal emphasis on the fears and worries of the person with diabetes and those of the relatives is an important step towards recognizing how important the whole family is when it comes to daily diabetes management and achieving the genuine involvement of the whole family:

Third round of analysis: how should we approach these problem domains?

After the first open analysis and the subsequent analysis of the six individual problem domains, we did a cross-analysis of the combined findings of the six domains described above. In this analysis, we looked specifically at common themes – with a focus on possible ways of approaching these problem domains in healthcare practice.

Constructive communication makes it easier to relate type 2 diabetes to health identities. The analysis showed us that positive, constructive communication is a direct and very significant motivating factor in making and especially maintaining lifestyle changes. It is also evident that when communication is negative, it is de-motivating. Clear communicative structures that ensure a communicative flow motivate automatic involvement and make it easier to relate any diabetes issue to health identities, and thereby also easier to understand and relate to new imaginaries and expectations related to type 2 diabetes in the family. The analysis shows us that healthcare professionals who focus on presenting information and education in ways that reinforce positive elements of the communicative structures in a given family are likely to be perceived as more authentic and, thereby, the information they provide is likely to be considered more relevant.

When information is presented in authentic ways, acquiring knowledge is less demanding. Acquiring knowledge was often mentioned as an incentive for lifestyle change and for supporting each other. However, it was also mentioned several times that knowledge could potentially have a negative effect when it is associated with doubt and uncertainty. Whether or not more knowledge was perceived as a motivating factor depended on the individual family's health identity and how they, accordingly, acquire and share knowledge. Some families had created a common self-understanding as a healthconscious entity for which health knowledge and diabetes information were automatically relevant and important. Other families had a self-understanding based on their unhealthiness, and they found the same information difficult and rather impossible to relate to their daily life. Many families reported that they were not motivated to seek out knowledge and that it really demanded too much effort to engage with complicated knowledge. When the information was presented in authentic ways or had authentic contents with direct relevance to the family in question, the task of acquiring knowledge was seen as less demanding.

It is essential to make the roles in a family with type 2 diabetes appear authentic. Role confusion is inextricably linked to communication. Not understanding or accepting the role – either as a person with type 2 diabetes or as a close relative to this person – impedes communication and involvement and often creates frustration and misunderstanding, which

The close relatives often have their own fears and worries that are just as important to discuss. It's often fears and worries that the one with diabetes doesn't have at all. (Healthcare professional – workshop 4/participant 4)

can make it close to impossible to relate the roles to existing health identities. But the opposite also applies: in families with no mutual involvement, strained communicative structures and incoherent health identities, it is often more difficult to accept and understand new roles and relational structures. The data show that worries and fears tend to arise when mutual roles and responsibilities are unclear or misunderstood, which may create communicative problems and frustration. For the healthcare professional, there is a twofold challenge in relation to role confusion: it is essential to make the roles in a family with type 2 diabetes appear authentic and possible to relate to for the individual family members – and in order to do that, the healthcare professional needs to present the information and education in a way that is deemed authentic by the family and the individual family members.

Focusing on the problem domains can link family health identity to healthcare authenticity. Thus, when it comes to generating involvement in families with type 2 diabetes, it is useful to look at how family health identity can be linked to healthcare authenticity. The data strongly suggest that this link can be achieved by focusing on the six problem domains. Focusing on communicating, supporting, acquiring and sharing knowledge, acting constructively in everyday life, performing and understanding roles and reducing worries will affect the degree of involvement in the family. The interconnectedness means that actively working with one domain will automatically affect the other five domains. This is also evident in how workshop participants described a negative spiral, where the inability to succeed in one domain severely affected other domains.

Every family will perceive different aspects as authentic based on their own health identity. Striving for authenticity in healthcare settings is difficult because every individual family will perceive different aspects as authentic based on their own health identity. So how can we attain a perpetual focus on authenticity and how can we maintain this sense of authenticity so that families will not lose their motivation, thereby affecting the problem domains negatively? The main question to be asked by the healthcare professional is: What is needed in this particular family to create the involvement that will make the problem domains (which will be stressed differently from family to family) authentically approachable for the healthcare professional? Or posed in a slightly different way: How can healthcare professionals approach the problem domains in ways that involve the whole family in meaningful and authentic ways?

The answers to these questions will depend on the characteristics of each individual family. The data do suggest, however, that a perpetual focus on family health identity and healthcare authenticity is a valid way for healthcare professionals to approach family problems in relation to mutual involvement – and thereby to catalyze involvement by relating the intervention or education (thereby making it authentic) to the health identity of the particular family. The study has produced important knowledge about how family involvement in life with type 2 diabetes can be supported in healthcare practice as well as in research and theory. The six concrete problem domains, combined with a focus on family health identity and healthcare authenticity, function well as approachable areas when the focus is on generating family involvement.

Our findings confirm that family involvement is indeed a complex matter that is characterized by confusion and often by unclear structures - a matter that calls for complexityoriented approaches. The present findings on misguided support and the ensuing communicative problems are very much in line with the findings of Mayberry and Osborn,³ Khan et al.4 and Stephens et al.5 The interdependent connectedness of the six problem domains and the differences in terms of how these domains apply to the individual families and their challenges in relation to life with type 2 diabetes further amplify this complexity. This is closely related to Badr et al.'s¹⁵ research on interconnected relationships and caregiving roles as well as to Scabini and Manzi's16 findings on mutual differentiation processes. The evident identification processes within families also support the use of a family history approach to preventing worry and fear and motivating positive prevention outcomes. The present findings on intra-familial sharing of knowledge highlight the importance of focusing on issues concerning lack of perceived disease relevance, as described by Myers et al.¹²

The strengths of our study include its highly comprehensive empirical base, consisting of 10 workshops with a total of 38 diverse family members and 37 equally diverse healthcare professionals involved in multiple parallel sessions. This provided us with ample data to carry out three thorough rounds of analysis. Another strength is the flexible yet structured nature of the analytic method, which enabled us to focus simultaneously on the families' problems and the healthcare professionals' ways of approaching these needs. The use of a comprehensive body of empirical data as well as an equally comprehensive theoretical framework renders the findings both empirically and theoretically solid and therefore applicable to various settings and contexts.

Limitations include the risk of the volunteering families being among those with substantial resources and with a fair amount of existing mutual involvement. We have taken this risk into account in our analysis and interpretation. Among the participating families there were, however, significant variations in terms of their apparent resourcefulness and resilience. Because data derived from workshops often tend to reflect consensus rather than in-depth aspects of individual self-interpretations, the study might have benefited from the inclusion of individual interviews with family members as well as healthcare professionals. That being said, a great deal of diversity in opinions and self-understandings emerged in the workshop data. The study has opened up several potentially interesting perspectives for further investigations into aspects of family life with type 2 diabetes. The connection between health identity and health behaviour needs to be studied more closely and would be relevant to look at using health pedagogical theories on action competence.²⁸ Inter-relational family contexts could be studied more explicitly if they were related to studies of social capital and health, and looking at our data using contemporary research on health inequalities could also be relevant in elucidating how type 2 diabetes affects families more broadly.^{29,30} A direct focus on family history would bring future studies closer to studies on narrative identity.^{31,32} This would be a way of looking at the connection between past, present and future health and the problems concerning lack of perceived disease relevance.

This study touches upon familial challenges concerning prevention and increased attention to early diagnosis. The findings on problem domains as well as the link between family health identity and healthcare authenticity can potentially be used to address these issues. There is, however, a need for further studies into the specifics of these important issues, as this study clearly shows us that the family is a relevant setting to approach when working with prevention and early diagnosis of type 2 diabetes.

Declaration of conflicting interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship and/or publication of this article.

Ethical approval

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Informed consent

Written informed consent was obtained from all subjects before the study.

References

- Kovacs Burns K, Nicolucci A, Holt RI, et al. Diabetes attitudes, wishes and needs second study (DAWN2TM): crossnational benchmarking indicators for family members living with people with diabetes. *Diabet Med* 2013; 30(7): 778–788.
- Torenholt R, Schwennesen N and Willaing I. Lost in translation: the role of family in interventions among adults with diabetes: a systematic review. *Diabet Med* 2014; 31(1): 15–23.
- Mayberry LS and Osborn CY. Family involvement is helpful and harmful to patients' self-care and glycemic control. *Patient Educ Couns* 2014; 97: 418–425.
- Khan CM, Stephens MAP, Franks MM, et al. Influences of spousal support and control on diabetes management through physical activity. *Health Psychol* 2013; 32(7): 739–747.

- Stephens MAP, Franks MM, Rook KS, et al. Spouses' attempts to regulate day-to-day dietary adherence among patients with type 2 diabetes. *Health Psychol* 2013; 32(10): 1029–1037.
- Mayberry LS and Osborn CY. Family support, medication adherence, and glycemic control among adults with type 2 diabetes. *Diabetes Care* 2012; 35: 1239–1245.
- Samuel-Hodge CD, Cene CW, Corsino L, et al. Family diabetes matters: a view from the other side. *J Gen Intern Med* 2013; 28(3): 428–435.
- 8. White P, Smith SM and O'Dowd T. Living with Type 2 diabetes: a family perspective. *Diabet Med* 2007; 24: 796–801.
- Weijnen CF, Rich SS, Meigs JB, et al. Risk of diabetes in siblings of index cases with type 2 diabetes: implications for genetic studies. *Diabet Med* 2002; 19(1): 41–50.
- Khan A, Lasker SS and Chowdhury TA. Are spouses of patients with type 2 diabetes at increased risk of developing diabetes? *Diabetes Care* 2003; 26(3): 710–712.
- Pierce M, Keen H and Bradley C. Risk of diabetes in offspring of parents with non-insulin-dependent diabetes. *Diabet Med* 1995; 12(1): 6–13.
- Myers MF, Fernandes SL, Arduser L, et al. Talking about type 2 diabetes: family communication from the perspective of atrisk relatives. *Diabetes Educ* 2015; 41(6): 716–728.
- Heideman WH, de Wit M, Middelkoop BJ, et al. Diabetes risk reduction in overweight first degree relatives of type 2 diabetes patients: effects of a low-intensive lifestyle education program (DiAlert) A randomized controlled trial. *Patient Educ Couns* 2015; 98(4): 476–483.
- Godino JG, van Sluijs EMF, Sutton S, et al. Understanding perceived risk of type 2 diabetes in healthy middle-aged adults: a cross-sectional study of associations with modelled risk, clinical risk factors, and psychological factors. *Diabetes Res Clin Pract* 2014; 106: 412–419.
- 15. Badr H, Acitelli LK and Taylor CLC. Does couple identity mediate the stress experienced by caregiving spouses? *Psychol Health* 2007; 22(2): 211–229.
- Scabini E and Manzi C. Family processes and identity. In: Schwartz SJ, Luyckx K and Vignoles VL (eds) *Handbook of identity theory and research*. New York: Springer, 2011, pp. 565–584.
- Grabowski D and Rasmussen KK. Adolescents' health identities: a qualitative and theoretical study of health education courses. *Soc Sci Med* 2014; 120: 67–75.
- Grabowski D. Health identity: theoretical and empirical development of a health education concept. *J Socio Res* 2015; 6(1): 141–157.
- Rasmussen J. Textual interpretation and complexity radical hermeneutics. Nord Pedagog 2004; 24(3): 177–194.
- Cranton PA and Carusetta E. Developing authenticity as a transformative process. *J Transform Educ* 2004; 2(4): 276– 293.
- Kreber C, Klampfleitner M, McCune V, et al. What do you mean by 'authentic'? A comparative review of the literature on conceptions of authenticity in teaching. *Adult Educ Quart* 2007; 58(1): 22–43.
- 22. Taylor C. *The ethics of authenticity*. Cambridge, MA: Harvard University Press, 1991.
- Barab SA, Squire KD and Dueber W. A co-evolutionary model for supporting the emergence of authenticity. *Educ Technol Res Dev* 2000; 48(2): 37–62.

- 24. Dewey J. *Experience and education*. New York: Kappa Delta Pi, 1938.
- 25. Waterman AS. Identity formation: discovery or creation? *J Early Adolescence* 1984; 4(4): 329–341.
- 26. Taylor C. *Modern social imaginaries*. Durham, NC: Duke University Press, 2004.
- Luhmann N. Social systems. Palo Alto, CA: Stanford University Press, 1995.
- 28. Schnack K and Jensen BB. The action competence approach in environmental education. *Environ Educ Res* 1997; 3(2): 163–178.
- 29. Ferlander S. The importance of different forms of social capital for health. *Acta Sociol* 2007; 50: 115–128.

- Diderichsen F, Andersen I and Manuel C. Health inequality: determinants and policies. *Scand J Public Healt* 2012; 40(8): 12–105.
- Reese E, Yan C, Jack F, et al. Emerging identities: narrative and self from early childhood to early adolescence. In: McLean KC and Pasupathi M (eds) *Narrative development in adolescence*. New York: Springer, 2010, pp. 23–43.
- 32. Negele A and Habermas T. Self-continuity across developmental change in and of repeated life narratives. In: McLean KC and Pasupathi M (eds) *Narrative development in adolescence*. New York: Springer, 2010, pp. 1–21.